

Conclusion. A new scale that evaluates sense of security with regard to cancer care was developed. Future studies should examine whether establishing a regional health care system that provides quality palliative care could improve the sense of security of the general population. *J Pain Symptom Manage* 2012;43:218–225. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Sense of security, palliative care, region, quality of care, general population

Introduction

Cancer is a serious disease affecting the lives of many people. In Japan, cancer affects half of the population (55% of males and 41% of females) throughout their lifetime¹ and is the cause of about 30% of all deaths.² It is essential that quality care is available for cancer patients. Outcomes of care for cancer patients have been measured using various indicators such as symptoms,^{3,4} prognosis, quality of life,^{5,6} quality of care,^{7,8} patient satisfaction,^{9,10} and family satisfaction;¹¹ however, there are no indicators that assess the overall availability of care, which could be used, for example, to compare regions.

Having a sense of security about the availability of high-quality care is very important for cancer patients and their families.¹² A sense of security should be evaluated from the perspective of the general population living in a region, in addition to cancer patients and their families. These perspectives reflect the quality of the regional system for providing health care services, and the awareness among the population of the services provided by the system. As part of quality assurance of regional cancer care, a sense of security among the general population is important.

Regarding the concept of a sense of security, Funk et al.¹² indicated that a feeling of security among family caregivers of cancer patients consisted of trust in competent professionals; timely access to needed care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals. The domain of “access to care” encompasses a sense of feeling supported and the perceived access to care.¹² Milberg et al.^{13,14} also suggested that having competent staff with a good attitude, access to care 24 hours a day, and being at home contributed to

a feeling of security among family caregivers. According to these proposed concepts, security is not only just trust in an individual health care professional but also a generalized sense of institutional trust in the health care system that makes people feel supported.¹² However, the concept of a sense of security has not been explicitly validated.

The aims of this study were 1) to develop a scale for the general population in regions of Japan that evaluates the sense of feelings of support and security regarding cancer care, and 2) to identify factors associated with a sense of security in those regions. This study is new in that the scale to assess the sense of security is measured from the perspective of the general population in a region and includes both trust in competent health care professionals and in the regional health care system, as proposed by Funk et al.¹²

Methods

This study was conducted as a part of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, launched by the Ministry of Health, Labor, and Welfare in Japan.^{15,16} The OPTIM study is a regional intervention trial with the aim of establishing a regional palliative care model in four areas of Japan: a large urban area (Chiba: Kashiwa, Nagareyama, and Abiko City), a smaller urban area (Shizuoka: Hamamatsu City), and two rural areas (Nagasaki: Nagasaki City, and Yamagata: Tsuruoka and Mikawa City). In Chiba, Shizuoka, and Nagasaki, palliative care services are available; in Yamagata, such services are sparse.

We administered a cross-sectional anonymous questionnaire. In the questionnaire, we explained the aim of the study and regarded

the completion and returning of the questionnaire as consent to participate. The ethical and scientific validity of this study was confirmed by the institutional review board independently from the research project, which was organized by the Japan Cancer Society, the organization responsible for conducting the OPTIM study.

Population and Procedures

We identified 8000 subjects, 40–80 years of age, within the general population, using a stratified two-stage random sampling of residents in the four regions (2000 subjects in each area). We mailed questionnaires to potential participants in July 2007, and if the questionnaire was not returned, we sent a reminder postcard.

Measurements

We developed a questionnaire regarding the sense of security through discussions based on previous studies.^{12–14} The questionnaire comprised five statements about the characteristics of health care professionals who provide adequate treatment and care (“competent professionals”) and adequate access to health care resources to feel supported (“timely access to needed care”), which are components indicated by Funk et al.¹² We did not include the “caregiver’s identity and self-worth¹²” in the questionnaire because the intended use of this scale in the OPTIM study was to measure the change in the level of competency of professionals and timely access to needed care as a result of the intervention for improving regional palliative care. The face validity of the questions was assessed based on full agreement of the authors.

The questionnaire statements were as follows: If I get cancer 1) I would feel secure in receiving cancer treatment, 2) my pain would be well relieved, 3) medical staff will adequately respond to my concerns and pain, 4) I would feel secure as a variety of medical care services are available, and 5) I would feel secure in receiving care at home. The translation from Japanese to English was done by a translation/back-translation procedure as follows: the questions were translated into English by a proficient translator; this translation was supervised by a bilingual person and modified. Subsequently, this prototype was translated

into Japanese by two researchers other than the authors. The back-translation was compared with the original Japanese questionnaire, and the authors approved it. We asked participants to rate their level of agreement with the statements on a seven-point Likert scale (1: strongly disagree, 2: disagree, 3: slightly disagree, 4: not sure, 5: slightly agree, 6: agree, and 7: strongly agree).

The demographic data, such as area where the respondent lived, age, gender, duration of residence in the region, current treatment of health problems, diagnosis of cancer (during or after treatment), family members’ experiences of cancer, and knowledge about palliative care also were included in the questionnaire.

Statistical Analyses

First, we conducted descriptive analyses of demographic data and responses concerning the sense of security regarding cancer care in the designated region.

Scale Development. To examine feasibility, we considered the rate of missing data for questions regarding sense of security. We then used exploratory factor analysis using the principal factor method for questions on sense of security; the factorial validity of the scale was examined. To assess the reliability of the scale, we calculated Cronbach’s α coefficients.

The scale score was calculated by summing the points for the five items because the score was regarded as normally distributed. We set 25 points, which is the sum of five Number 5 ratings (“slightly agree”), or more as the cutoff on the sense of security scale to identify persons who felt secure.

Related Factors. To identify factors associated with a sense of security, univariate analyses were conducted using analysis of variance, the unpaired *t*-test, Pearson product-moment correlation coefficient, and Spearman rank correlation coefficient, where appropriate. Thereafter, the association of each hypothesized factor with the sense of security score was determined using multiple regression analysis.

Statistical analysis was performed using SAS Version 9.1 (SAS Institute, Inc., Cary, NC). The significance level was set at <0.05 (two-tailed).

Results

Characteristics of Participants

Of the 8000 questionnaires sent out, 26 were undeliverable and 3984 were returned. Among the respondents, 254 were excluded because of missing data for items regarding sense of security, and 3730 responses were analyzed (effective response rate: 46.8%). There was a significant difference in the response rate among the areas (Yamagata, 47%; Chiba, 53%; Shizuoka, 44%; and Nagasaki, 42%; Chi-squared test, $P < 0.001$). Table 1 summarizes the characteristics of the respondents.

Distribution of the Sense of Security in the Region

Table 2 shows the distribution of responses regarding the sense of security. Although about 60% of the respondents (sum of "strongly agree," "agree," and "slightly agree") believed that they would be treated appropriately for cancer, less than half of the respondents believed that the treatment for pain and distress and the availability of health care services, including home care, would be sufficient.

Feasibility

The rate of missing values for the five items regarding the sense of security was 1.5%–3.5%.

Exploratory Factor Analysis

According to the results of the exploratory factor analysis, the five items regarding the sense of security were aggregated into one factor (Table 3). Cronbach's α was 0.91.

Table 1
Characteristics of Respondents ($n = 3730$)

Characteristic	<i>n</i> (%)
Area	
Yamagata	943 (25)
Chiba	1061 (28)
Shizuoka	877 (24)
Nagasaki	849 (23)
Gender	
Male	1648 (45)
Female	2012 (55)
Age (years), mean (\pm SD)	59.6 (\pm 10.5)
Duration of residence in the region	
Less than one year	42 (1)
One to five years	141 (4)
More than five years	3457 (95)
Treated for health problems	1959 (54)
Have cancer	177 (5)
Family members' experiences of cancer	2008 (55)
Awareness of palliative care	523 (15)

SD = standard deviation.

Percentages for each item were calculated after excluding missing values.

Related Factors

Univariate Analyses. The association of each demographic factor with the sense of security score, which was calculated by summing the points of the five items, was examined using univariate analyses, and the results are shown in Table 4. The difference in the sense of security among the areas was significant ($P < 0.001$). Other factors associated with a higher score for the sense of security were an older age ($P < 0.001$), current treatment for a health problem ($P < 0.001$), having cancer ($P < 0.001$), and no family history of cancer ($P = 0.005$). When examining correlations among variables, a family history of cancer was associated with gender (females had more

Table 2
Distribution of Responses for Sense of Security Regarding Cancer Care ($n = 3730$)

If I get cancer:	Strongly Disagree (%)	Disagree (%)	Slightly Disagree (%)	Not Sure (%)	Slightly Agree (%)	Agree (%)	Strongly Agree (%)	Total Agreement ^a (%)
(1) I would feel secure in receiving cancer treatment.	3	10	9	17	26	30	6	61
(2) My pain would be well relieved.	4	18	13	24	23	17	2	41
(3) Medical staff will adequately respond to my concerns and pain.	3	14	13	23	26	19	2	46
(4) I would feel secure as a variety of medical care services are available.	5	17	14	29	21	12	2	35
(5) I would feel secure in receiving care at home.	9	26	16	26	15	7	1	23

Percentages for each item were calculated after excluding missing values.

^aSum of "slightly agree," "agree," and "strongly agree."

Table 3
Exploratory Factor Analysis (n = 3587)

If I get cancer:	Factor 1	Communality
(1) I would feel secure in receiving cancer treatment.	0.82	0.67
(2) My pain would be well relieved.	0.88	0.77
(3) Medical staff will adequately respond to my concerns and pain.	0.91	0.83
(4) I would feel secure as a variety of medical care services are available.	0.90	0.82
(5) I would feel secure in receiving care at home.	0.77	0.59

Proportion of variance explained = 73.5%.

experiences of family cancer) and having a health problem was associated with age and having cancer ($P < 0.001$, respectively).

Multiple Regression Analyses. The results of multiple regression analyses are shown in Table 5.

Table 4
Factors Related to Sense of Security According to Univariate Analyses (n = 3587)

Variable	Sense of Security Score Mean (SD)	Pvalue
Area		
Yamagata	17.7 (7.1)	<0.001 ^a
Chiba	19.8 (6.3)	
Shizuoka	21.3 (6.2)	
Nagasaki	19.9 (6.6)	
Gender		
Male	20.0 (6.2)	0.571 ^b
Female	20.1 (6.3)	
Age	0.225 ^c	<0.001
Duration of residence in the region	-0.015 ^d	0.373
Treated for health problems		
Yes	20.6 (6.3)	<0.001 ^b
No	19.5 (6.2)	
Have cancer		
Yes	23.1 (5.7)	<0.001 ^b
No	19.9 (6.3)	
Family members' experiences of cancer		
Yes	19.5 (6.4)	0.005 ^b
No	20.1 (6.2)	
Awareness of palliative care		
Yes	20.1 (6.7)	0.666 ^b
No	20.0 (6.2)	

SD = standard deviation.

^aAnalysis of variance.

^bt-test.

^cPearson product-moment correlation coefficient.

^dSpearman rank correlation coefficient.

Table 5
Factors Related to Sense of Security According to Multiple Regression Analyses (n = 3419)

Independent Variable	β	P-value
Area		
Yamagata	Reference	—
Chiba	0.143	<0.001
Shizuoka	0.242	<0.001
Nagasaki	0.140	<0.001
Gender		
Male	Reference	—
Female	0.035	0.035
Age	0.155	<0.001
Duration of residence in the region		
Less than one year	Reference	—
One to five years	0.023	0.436
More than five years	-0.004	0.898
Treated for health problems	0.015	0.389
Have cancer	0.090	<0.001
Family members' experiences of cancer	-0.028	0.096
Awareness of palliative care	-0.011	0.528

Determination coefficient: $R^2 = 0.068$.

The Yamagata area showed a significantly smaller score for the sense of security compared with the other areas ($P < 0.001$). Female gender ($P = 0.035$), older age ($P < 0.001$), and diagnosis of cancer ($P < 0.001$) were associated with a high score for sense of security. The associations of these variables, other than the area and age, were not strong, and the determination coefficient was small (0.068).

Discussion

In this study, we developed a scale to evaluate the general population in regions of Japan to assess their feelings of support and security regarding cancer care. The scale was constructed using one factor, and showed good face validity based on the full agreement of the authors, and factorial validity and internal consistency on factor analysis. The sense of security in the Yamagata area was poor compared with that in the other three areas. Being female, of an older age, and having cancer were associated with a strong sense of security. Additionally, more than half of the respondents felt uneasy (i.e., "strongly disagree," "disagree," "slightly disagree," and "not sure") about the availability of adequate treatment for pain and distress caused by cancer and of the types of health

care services available (e.g., home care). These responses suggest that many people were unsure about the adequacy of regional cancer care.

To our knowledge, this is the first study to evaluate the sense of security regarding cancer care from the perspective of the general population. In the Yamagata area, where specialized palliative care services were not available at the time of the survey, the sense of security was relatively poor. This result suggests that the scale could reflect the adequacy of the regional system for providing health care services, thus suggesting good known-group validity.

In the scale developed in this study, the sense of security of the general population comprised trust in health care professionals to adequately respond to patients' pain and distress from cancer, and feeling that various medical and care services are readily available, even at home.¹² To improve the sense of security in a region, it is important for the general population to feel supported; thus, health care professionals should be educated in cancer and palliative care, palliative and other care services should be available, and these services should be accessible to the general population. This new scale would be a useful endpoint for evaluating the comprehensive sense of security in the general population of a region. It also may be used as an indicator of the adequacy of health care services (including the competency of health care professionals and accessibility to care) provided in the region and awareness of the services among the general population.

Furthermore, the scale, although developed to target the general population, also could be used with cancer patients and their families. Whereas the questionnaire queried the general population about a hypothetical diagnosis of cancer, the surveys of cancer patients and their families using this instrument could collect more practical data on the sense of security based on care already received.

We also identified factors other than "area" that are associated with a sense of security, to be able to apply the OPTIM model effectively to other regions of Japan in the future. Older age, female gender, and a diagnosis of cancer were associated with a strong sense of security; having health problems and a family member's experience of cancer, which were associated with a sense of security on univariate but not

multivariate analysis, might be confounding factors of age and having cancer, and gender, respectively.

First, the results for age and gender were comparable to previous studies regarding patient satisfaction with health care, which indicated that older patients were more satisfied with their care than younger ones, but the association of gender and satisfaction differed.¹⁷⁻¹⁹ Our results showing that older people had a strong sense of security are supported by the results of a previous study in which older individuals remembered an earlier less accessible health care system and so were less ready to criticize, and that they did not have high expectations.¹⁸ Additionally, because many older persons lead a community-based life compared with younger ones, they may have easy access to regional health care; consequently they may feel more secure regarding its accessibility. For gender, a previous study put forward a reason why females may be more satisfied with the health care they have received than males; the level of communication with health care staff affected patient satisfaction, and females communicated more with staff than males.²⁰ In the present study, however, the scores for sense of security were almost equal between males and females, and the standardized partial regression coefficient of the multiple regression analysis was small. Further analyses regarding the influence of gender are needed.

Second, the subjects with cancer felt more secure regarding cancer care than those without cancer. This result suggests that, whereas a person without cancer may feel a vague anxiety about cancer and its care, once a person gets cancer and has experienced receiving care, he or she may feel secure because the level of individual treatment and care in Japan is of a relatively high quality. On the other hand, subjects with a family member who had cancer had a poor sense of security compared with those without such experience, although the difference was not significant on multivariate analysis. This situation might be a result of experiencing earlier cancer care in Japan, which was poor. Doctors did not tell patients they had cancer, and pain control was inadequate. Consequently, many patients died a painful death. The result may suggest that individuals who lost a family member (mostly parents) to cancer, in times past, saw their pain and distress; therefore, they have

the impression that cancer causes great distress and so a poor sense of security regarding cancer care. However, in Japan, palliative care teams became covered by National Medical Insurance in 2002, and the Cancer Control Act was established in 2007; as a result, palliative care has progressed so that more effective treatments are available.

Nonetheless, the association of each variable with a sense of security was not strong, and the determination coefficient was small. There should be factors associated with a sense of security other than those measured in this study. To identify effective strategies for improving the sense of security in the general population within a region, future studies should look at the association of more detailed characteristics of the respondents with the sense of security. For example, if persons with negative perceptions about palliative care (such as "a place where people only wait to die")²¹ have a low sense of security, strategies that specifically educate about palliative care and improve the perceptions of such persons would be needed. Also, if persons who do not know of the availability of specialized palliative care services and other care resources (e.g., home care) in the region have a low sense of security, strategies that disseminate knowledge on the availability of services would be needed.

This study had several limitations. First, the content validity and test-retest reliability were not confirmed; further study is needed. Generally, the reliability of a scale should be verified using the test-retest method. However, Cronbach's α (internal consistency) also can be used as an indicator of reliability; if Cronbach's α is high, the coefficient of test-retest reliability also would be expected to be high.

Second, although we considered that the scale for the sense of security could be a measure of the adequacy of the system for providing health care services and the awareness among the population of the services, the construct validity has not been confirmed. Future studies should compare the sense of security with other indicators regarding the quality of the regional health care system, such as death at home, the number of patients receiving specialized palliative care, and evaluation of patients and the bereaved family, which were not measured during the study period but are measured now in the OPTIM study.¹⁵

Third, the response rate of the survey was not high, the difference in response rate among the areas was significant, and we could not clarify the characteristics of nonresponders; therefore, a response bias may exist. However, because the response rate of opinion surveys in the general population in Japan is generally about 50%,^{8,22-24} the response rate of the study may be acceptable.

In conclusion, this study developed a new scale to evaluate feelings of support and security regarding cancer care in regions of Japan. This scale may be a useful endpoint for studies on the comprehensive sense of security, as well as adequacy of the system for providing health care services for cancer in a region, and awareness among the general population of the services. The OPTIM study is an intervention trial for improving these endpoints; we are awaiting the results of this intervention.

Disclosures and Acknowledgments

This study was supported by a grant-in-aid for the Third Term Comprehensive Strategy for Cancer Control in Japan. The funder was not involved in the conduct of this study or its submission. The authors declare no conflicts of interest.

The authors would like to express special thanks to Meiko Kuriya, Kazuki Sato, and Yoko Hanada for their expert comments.

References

1. Foundation for Promotion of Cancer Research. Cancer statistics in Japan. Tokyo, Japan: Foundation for Promotion of Cancer Research, 2009.
2. Statistics and Information Department, Ministers Secretariat, Ministry of Health, Labor, and Welfare. Vital statistics of Japan, 2009. [in Japanese]. Tokyo, Japan: Ministry of Health, Labor, and Welfare, 2010.
3. Okuyama T, Wang X, Akechi T, et al. Japanese version of the M. D. Anderson Symptom Inventory: a validation study. *J Pain Symptom Manage* 2003;26:1093-1104.
4. Miyashita M, Yasuda M, Baba R, et al. Inter-rater reliability of proxy simple symptom assessment scale between physician and nurse: a hospital-based palliative care team setting. *Eur J Cancer Care (Engl)* 2010;19:124-130.
5. Cella D, Tulsky D, Gray G, et al. The Functional Assessment of Cancer Therapy scale: development

and validation of the general measure. *J Clin Oncol* 1993;11:570–579.

6. Aaronson N, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365–376.

7. Morita T, Hirai K, Sakaguchi Y, et al. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage* 2004;27:492–501.

8. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007;18:1090–1097.

9. Lo C, Burman D, Hales S, et al. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. *Eur J Cancer* 2009;45:3182–3188.

10. Brédart A, Sultan S, Regnault A. Patient satisfaction instruments for cancer clinical research or practice. *Expert Rev Pharmacoecon Outcomes Res* 2010;10:129–141.

11. Morita T, Chihara S, Kashiwagi T, Quality Audit Committee of the Japanese Association of Hospice and Palliative Care Units. A scale to measure satisfaction of bereaved family receiving inpatient palliative care. *Palliat Med* 2002;16:141–150.

12. Funk L, Allan D, Stajduhar K. Palliative family caregivers' accounts of health care experiences: the importance of "security". *Palliat Support Care* 2009;7:435–447.

13. Milberg A, Strang P. Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliat Med* 2000;14:533–534.

14. Milberg A, Strang P, Carlsson M, Börjesson S. Advanced palliative home care: next-of-kin's perspective. *J Palliat Med* 2003;6:749–756.

15. Yamagishi A, Morita T, Miyashita M, et al. Palliative care in Japan: current status and a nationwide

challenge to improve palliative care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. *Am J Hosp Palliat Care* 2008;25:412–418.

16. Eguchi K. Development of palliative medicine for cancer patients in Japan: from isolated voluntary effort to integrated multidisciplinary network. *Jpn J Clin Oncol* 2010;40:870–875.

17. Lewis J. Patient views on quality care in general practice: literature review. *Soc Sci Med* 1994;39:655–670.

18. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med* 1997;45:1829–1843.

19. Morita T, Chihara S, Kashiwagi T, Quality Audit Committee of the Japanese Association of Hospice and Palliative Care Units. Family satisfaction with inpatient palliative care in Japan. *Palliat Med* 2002;16:185–193.

20. Hall J, Roter D, Katz N. Meta-analysis of correlates of provider behavior in medical encounters. *Med Care* 1988;26:657–675.

21. Sanjo M, Miyashita M, Morita T, et al. Perceptions of specialized inpatient palliative care: a population-based survey in Japan. *J Pain Symptom Manage* 2008;35:275–282.

22. Miyata H, Tachimori H, Takahashi M, Saito T, Kai I. Disclosure of cancer diagnosis and prognosis: a survey of the general public's attitudes toward doctors and family holding discretionary powers. *BMC Med Ethics* 2004;5:E7.

23. Sanjo M, Miyashita M, Morita T, et al. Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Ann Oncol* 2007;18:1539–1547.

24. Morita T, Miyashita M, Shibagaki M, et al. Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: a population-based survey in Japan. *J Pain Symptom Manage* 2006;31:306–316.

Original Article

Providing Palliative Care for Cancer Patients: The Views and Exposure of Community General Practitioners and District Nurses in Japan

Akemi Yamagishi, PhD, RN, Tatsuya Morita, MD, Mitsunori Miyashita, RN, PhD, Takayuki Ichikawa, MA, Nobuya Akizuki, MD, PhD, Yutaka Shirahige, MD, PhD, Miki Akiyama, PhD, and Kenji Eguchi, MD, PhD

Department of Nursing (A.Y.), Seirei Christopher University, Hamamatsu, Shizuoka; Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka; Department of Palliative Nursing (M.M.), Health Sciences, Tohoku University Graduate School of Medicine, Sendai, Miyagi; Department of Adult Nursing/Palliative Care Nursing (T.I.), School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo; Psycho-Oncology Division (N.A.), Chiba Cancer Center, Chiba, Chiba; Shirahige Clinic (Y.S.), Nagasaki, Nagasaki; Faculty of Policy Management (M.A.), Keio University, Fujisawa; and Department of Internal Medicine (K.E.), Teikyo University School of Medicine, Tokyo, Japan

Abstract

Context. The role of general practitioners (GPs) and district nurses (DNs) is increasingly important to achieve dying at home.

Objectives. The primary aim of this region-based representative study was to clarify 1) clinical exposure of GPs and DNs to cancer patients dying at home, 2) availability of symptom control procedures, 3) willingness to participate in out-of-hours cooperation and palliative care consultation services, and 4) reasons for hospital admission of terminally ill cancer patients.

Methods. Questionnaires were sent to 1106 GP clinics and 70 district nursing services in four areas across Japan.

Results. Two hundred thirty-five GPs and 56 district nursing services responded. In total, 53% of GPs reported that they saw no cancer patients dying at home per year, and 40% had one to 10 such patients. In contrast, 31% of district nursing services cared for more than 10 cancer patients dying at home per year, and 59% had one to 10 such patients. Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available in more than 90% of district nursing services, whereas 35% of GPs reported that oral opioids were unavailable and 50% reported that subcutaneous opioids or haloperidol were unavailable. Sixty-seven percent of GPs and 93% of district nursing services were willing to use palliative care consultation services. Frequent reasons for admission were family burden of

Address correspondence to: Akemi Yamagishi, PhD, RN, Department of Nursing, Seirei Christopher University, 3453 Mikatahara, Kita-ku, Hamamatsu, Shizuoka

433-8558, Japan. E-mail: ayamagishi-ty@umin.ac.jp

Accepted for publication: March 4, 2011.

caregiving, unexpected change in physical condition, uncontrolled physical symptoms, and delirium.

Conclusion. Japanese GPs have little experience in caring for cancer patients dying at home, whereas DNs have more experience. To achieve quality palliative care programs for cancer patients at the regional level, educating GPs about opioids and psychiatric medications, easily available palliative care consultation services, systems to support home care technology, and coordinated systems to alleviate family burden is of importance. *J Pain Symptom Manage* 2012;43:59–67. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Home, general practitioner, district nurse, palliative care, community

Introduction

Dying at a preferred place is an important outcome for terminally ill cancer patients, and many patients prefer home as place of death across the world and in Japan.^{1,2} Specialized home care services appear to be effective in improving the patient's quality of life and ability to stay at home,^{3,4} but the rates of home death vary among countries. In Japan, only 6% of cancer deaths occurred at home in 2009.^{5,6}

A number of significant determining factors for achieving a home death have been identified by multiple empirical studies. These include patient and caregiver preference, intensity of home care services, and level of family support, as well as disease characteristics, patient's functional status, availability of hospital beds, rural or urban environment, and historical trend.^{7–10} These findings consistently stress the role of the community health care system in achieving home death, as well as the patient's and family's preference to stay at home.

Given the importance of community health services, the role of general practitioners (GPs) has become the focus of recent palliative care research.^{11–18} In these studies, current availability, barriers, and promising effective regional systems have been investigated using surveys of GPs and district nurses (DNs). On the whole, many GPs are willing to participate in palliative care and, in reality, see a relatively small number of palliative care patients each year.¹¹ At the same time, they experience the barriers of unfamiliar palliative care skills, medical technology, time constraints (especially out-of-hours demands), lack of

community services to reduce the family burden of caregiving, and lack of coordination and communication among community health care workers.¹¹

In Japan, palliative care is very strongly facilitated as a part of the government's cancer policy. Palliative care is increasingly seen as a part of comprehensive cancer treatment, and developing a regional model is urgently needed. Nonetheless, there have been very few large surveys about the availability of palliative care from community health care providers.^{19,20} Only one nationwide survey involved over 50,000 GP clinics and investigated their clinical exposure to palliative care, general willingness to be involved in palliative care, and knowledge about palliative care. In that survey, 60% of GPs had no experience in caring for cancer patients dying at home and 82% had no experience in prescribing opioids during the year but 47% expressed a willingness to provide medical care for terminally ill cancer patients dying at home. Furthermore, less than 20% were confident about palliative care skills, and less than half had correct knowledge about opioids.

This survey provides a nationwide overview of palliative care from the point of view of GPs, but the perspective of other professionals, especially DNs, is lacking; there are no data about the availability of symptom control procedures and willingness to participate in specific programs; and no region-based representative survey exists. We believe that gathering the views of GPs and DNs working from the same region is another valuable method to help understand

the reality and difficulties involved in palliative care for cancer patients at the regional level.

Therefore, this region-based comprehensive survey aimed to clarify 1) clinical exposure of GPs and DNs to cancer patients dying at home, 2) availability of symptom control procedures, 3) willingness to participate in out-of-hours cooperation and palliative care consultation services, and 4) reasons for admission of terminally ill cancer patients. The hypotheses of this study are that 1) in GPs, clinical exposure to cancer patients dying at home is not so high and some symptom control procedures are often unavailable, 2) in DNs, clinical exposure is high and symptom control procedures are generally available, 3) both GPs and DNs are willing to participate in out-of-hours cooperation and palliative care consultation services, and 4) DNs list various reasons for admission beyond medical reasons.

Health Care System Related to GPs, DNs, and Palliative Care in Japan

In Japan, there is no formal "family practice" or "general practitioner" system. Many clinic physicians functioning as GPs in the community are actually specialists, and after working at hospitals as specialists, they open their clinics under two or more specialty names irrespective of their certifications (e.g., a gastroenterologist usually can open a clinic under the names of "internal medicine," "pediatrics," and "gastroenterology"). The total number of clinics was about 90,000 in 2010, and all patients can visit any clinic and hospital they choose; they are not confined to their city or prefecture of residence.

Home nursing in Japan is provided through district nursing services. The number of district nursing services was 5763 in 2010. No expert palliative care nursing service (e.g., Macmillan nursing service) exists.

Since 1990, specialized palliative care service has been provided through palliative care units and inpatient hospices. The number of palliative care units was 208 (4153 beds) in 2010. Hospital palliative care teams are increasingly disseminated through cancer centers and general hospitals functioning as local cancer centers. The number of palliative care teams was about 500 in 2010. No community palliative care teams exist. Many health care professionals have regarded palliative care as a part of cancer

care. Although the concept of palliative care is not limited to cancer patients, we decided that this study should focus on palliative care for cancer patients.

Methods

This study was a cross-sectional mail survey of GPs and DNs in Japan and was a part of a regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. It was performed at the initial phase of the OPTIM study to explore the intervention protocols likely to be effective in each region; an overview of the OPTIM study is reported elsewhere.²¹

Questionnaires were sent to all GPs and DNs who met the inclusion criteria. No reminder or incentive was used. The ethical and scientific validity of this study was confirmed by the institutional review board.

Subjects

The survey was performed in four regions where the OPTIM study was used. Four areas with different palliative care systems were selected from across Japan: Tsuruoka (population 170,000, Yamagata prefecture); Kashiwa (population 670,000, Chiba prefecture); Hamamatsu (population 820,000, Shizuoka prefecture); and Nagasaki (population 450,000, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka had no formal specialized palliative care service at the time of the survey.

For this survey, we identified two groups of study subjects; a group of GPs and a group of DNs. The GPs all had a specialty of internal medicine, surgery, respiratory medicine, gastroenterology, urology, or gynecology. As there is no formal "family practice" or "general practitioner" system in Japan, we decided to include all specialties usually treating cancer patients. One questionnaire was sent to each GP clinic because many GP clinics are solo practice in Japan. The DNs comprised those working full time in a district nursing service. We had investigated the number of nurses

working at each district nursing service. Furthermore, we asked one representative DN from each district nursing service to answer questions relating to the service.

Measurements and Questionnaire

Because of a lack of validated tools and the exploratory nature of this study, the questionnaire was developed for this survey through literature review and discussions among authors.⁷⁻¹⁸ The clinical exposure of GPs and DNs to cancer patients dying at home was measured by 1) the number of cancer patients dying at home per year seen by each service (GP clinic or district nursing service), and 2) the predicted number of cancer patients dying at home likely to be seen by each service if out-of-hours cooperation among community health care providers and palliative care consultation services were available. The selected choices were none; one to five patients; six to 10 patients; 11 to 20 patients; or more than 20 patients per year. Furthermore, we investigated whether each service was available 24 hours a day.

The availability of symptom control procedures was measured using the choices "unavailable," "available if expert advice available," and "available" for each procedure, including oral opioids, subcutaneous opioids, subcutaneous haloperidol, home parenteral nutrition, peripheral intravenous infusion, hypodermoclysis, drainage of ascites or pleural effusion, and transfusion. "Expert" was described as expert only in the questionnaire because some physicians may not know palliative care specialists.

Willingness to participate in new regional systems was measured using two potential systems: out-of-hours cooperation among community health care providers (positive, neutral, and not interested), and palliative care consultation service in the community (want regular outreach visits, want on-demand consultation, and not interested). At the time of this study, neither system (out-of-hours cooperation among community health care providers, palliative care consultation in the community) was available in any of the four regions.

In addition, we asked all the DNs to consider the reason for admission of terminally ill cancer patients who they had cared for at home and rate the frequency of each of the following reasons, using a five-point Likert-type scale (1: none to 5: always): physical symptoms,

delirium, concern about out of hours, unexpected change in physical condition, family physician absent or inaccessible out of hours, unavailability of home care nurses, lack of informal caregivers, and family burden of caregiving.

Background data also were obtained from DNs concerning their age, clinical experience as a nurse, and their clinical experience as a DN. Data requested from GPs included their age, clinical experience, and whether their GP clinic was a certified home care clinic. Certified home care clinics are a recently developed medical system in Japan, whereby if the GP clinic has a 24-hour on-call system for patients at home, the clinic receives more payments from the national health care insurance.

Statistical Analyses

Data distributions, as well as 95% confidence intervals of the percentages, were calculated for all items. The difference among the regions was not statistically significant (data not shown) with the sample size small, and we determined to analyze all the data for this study.

Results

Of the 1106 GP clinics identified, a total of 235 (21%) responded. Responses were received from 22 of 88 clinics in Tsuruoka, 41 of 196 clinics in Kashiwa, 67 of 331 clinics in Hamamatsu, and 105 of 491 clinics in Nagasaki. Of the 70 district nursing services identified, a total of 56 services (80%) responded; a total of 115 responses were obtained from 270 DNs identified. Table 1 summarizes the background of the respondents.

Half of the GPs reported that they saw no cancer patients dying at home per year, and

Table 1
Background of Respondents

Characteristic	<i>n</i> ± SD
General practitioners (<i>n</i> = 235)	
Age (y)	57 ± 11
Clinical experience (y)	30 ± 11
Certified home care clinic, <i>n</i> (%)	30 (13)
District nurses (<i>n</i> = 115)	
Age (y)	42 ± 7.7
Clinical experience as a nurse (y)	18 ± 7.5
Clinical experience as a district nurse (y)	6.7 ± 4.5

Data are expressed as mean ± standard deviation unless otherwise noted.

Table 2
Number of Cancer Patients Dying at Home Seen by GP Clinics or District Nursing Services

Number of Cancer Patients Dying at Home (Per Year)	GP Clinics (n = 235)		District Nursing Services (n = 56)	
	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI
None	125 (53, 47–60)	113 (48, 42–55)	4 (7, 3–17)	6 (11, 5–22)
1–5	80 (34, 28–40)	80 (34, 28–40)	19 (34, 23–47)	12 (21, 13–34)
6–10	15 (6, 4–10)	19 (8, 5–12)	14 (25, 15–38)	13 (23, 14–36)
11–20	7 (3, 1–6)	9 (4, 2–7)	10 (18, 10–30)	11 (20, 11–32)
20 or more	1 (0.4, 0–2)	6 (3, 1–5)	7 (13, 6–24)	13 (23, 14–36)

95% CI = 95% confidence interval.

40% cared for one to 10 cancer patients dying at home (Table 2). Of the district nursing services, 30% cared for 10 or more cancer patients dying at home per year, and 60% cared for one to 10 such patients. Although 96% of district nursing services (n = 54) were available 24 hours a day, only 38% of GP clinics (n = 90) were available 24 hours a day.

If out-of-hours cooperation among community health care providers and a palliative care consultation service became available, the number of GPs and district nursing services that reported they would not see any cancer patients dying at home did not change considerably (53% to 48% for GP clinics, and 7% to 11% for district nursing services (Table 2). However, the number of GPs and district nursing services that reported they would see 20 or more cancer patients dying at home per year increased considerably, from 0.4% to 2.3% for GP clinics and 13% to 23% for district nursing services.

Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available from more than 80% of district nursing services if expert advice was available, whereas 34% of GPs reported oral opioids were unavailable, and approximately 50% reported subcutaneous opioids or haloperidol were unavailable, even if expert advice was available (Table 3). Peripheral intravenous infusion was available from about 70% of GPs and about 90% of district nursing services, whereas hypodermoclysis was available from less than 60% of GP clinics and about 70% of district nursing services. Drainage of ascites or pleural effusion and transfusions were rated as unavailable by

more than 50% of GP clinics and district nursing services.

Concerning the out-of-hours cooperation among community health care providers, only 20% or fewer of GP clinics and district nursing services reported feeling “positive,” and 35% of GPs reported no interest (Table 4). However, palliative care consultation service in the community was regarded as more necessary, with about half the GP clinics and district nursing services wanting on-demand consultation, and an additional 24% of GPs and 41% of district nursing services reporting that they wanted regular outreach visits.

Reasons for admission of terminally ill cancer patients that DNs had cared for at home are shown in Table 5. Family burden of caregiving was the most frequent reason given by DNs, with about 60% reporting this as “often” or “always.” The next most frequent reason was unexpected change in physical condition (about 40%), followed by uncontrolled physical symptoms (about 30%), and delirium (about 30%). Concern about out of hours, the family physician absent or inaccessible out of hours, lack of home care nurses, or lack of informal caregivers was infrequently listed.

Discussion

We believe this survey provides useful insights into the development of community palliative care services in Japan and also helps us understand how to deliver more effective palliative care through existing community health care services around the world.

Table 3
Availability of Symptom Control Procedures for GPs and District Nursing Services

Procedure Variation	GP Clinics (n = 235)			District Nursing Services (n = 56)		
	Unavailable n (%; 95% CI)	Available if Expert Advice Available n (%; 95% CI)	Available n (%; 95% CI)	Unavailable n (%; 95% CI)	Available if Expert Advice Available n (%; 95% CI)	Available n (%; 95% CI)
Oral opioids	81 (34, 29-41)	85 (36, 30-43)	59 (25, 20-31)	1 (2, 0-10)	30 (54, 41-66)	24 (43, 31-56)
Subcutaneous opioids	121 (51, 45-58)	82 (35, 29-41)	23 (10, 7-14)	6 (11, 0-22)	42 (75, 62-85)	6 (11, 5-22)
Subcutaneous haloperidol	113 (48, 42-55)	90 (38, 32-45)	24 (10, 7-15)	6 (11, 0-22)	42 (75, 62-85)	5 (9, 4-19)
Home parenteral nutrition	116 (49, 43-56)	68 (29, 23-35)	43 (18, 14-24)	3 (5, 2-15)	21 (38, 26-51)	32 (57, 44-69)
Peripheral intravenous infusion	57 (24, 19-30)	63 (27, 22-33)	104 (44, 38-51)	2 (4, 1-12)	18 (32, 21-45)	35 (63, 49-74)
Hypodermoclysis	95 (40, 34-47)	100 (43, 36-49)	33 (14, 10-19)	15 (27, 17-40)	35 (63, 49-74)	5 (9, 4-19)
Drainage of ascites/pleural effusion	118 (50, 44-57)	56 (24, 19-30)	52 (22, 17-28)	31 (55, 42-68)	20 (36, 24-49)	5 (9, 4-19)
Transfusion	131 (56, 49-62)	49 (21, 16-27)	47 (20, 15-26)	28 (50, 37-63)	24 (43, 31-56)	4 (7, 3-17)

95% CI = 95% confidence interval.

One of the most important results of this study was the finding that Japanese GPs had little exposure to cancer patients dying at home. This figure is comparable to the largest survey conducted to date in Japan, which reported that 60% of all GPs had no experience in caring for cancer patients who died at home.¹⁹ This is different than results from studies in Canada, the U.K., and Australia, which showed that almost all GPs in those countries have some experience in caring for terminally ill cancer patients dying at home.¹¹ One possible interpretation of our results is that many GPs in Japan are former "specialists" who worked in hospitals, and a considerable number of physicians are unfamiliar with managing cancer patients (e.g., cardiology). In addition, Japanese GPs have no formal responsibility in the health care system for caring for patients in the community of their clinics, and cancer patients usually receive medical treatments in hospitals. Nonetheless, a third of Japanese GPs had experience in caring for one to five terminally ill cancer patients dying at home per year. This result is consistent with previous findings from the U.K. and Australia, where a GP sees about five terminally ill cancer patients per year.¹¹ Our results highlight the difficulties faced by Japanese GPs in learning up-to-date skills in palliative care when they only have minimal exposure to terminally ill cancer patients. This finding suggests that easily available on-demand consultation services from palliative care experts are necessary.

In this survey, hypothetical out-of-hours cooperation among community health care providers and the availability of palliative care consultation services in the region did not noticeably increase the number of GPs that intended to see terminally ill cancer patients at home. In addition, 30% of GPs reported no interest in participating in or developing such regional palliative care services. This figure is very close to the finding from an Australian survey, which identified lack of interest as one of the most frequent reasons for GPs not participating in palliative care.¹² Similarly, a U.K. survey reported that about 30% of London GPs believed "palliative care at home should be handed over to specialists."¹³ In contrast, the number of GP clinics and district nursing services that reported they would care for 20 or more cancer patients dying at home considerably increased in

Table 4
Willingness to Participate in Out-of-Hours Cooperation and Palliative Care Expert Consultation

Item	GPs (n = 235), n (%), 95% CI)	District Nursing Services (n = 56), n (%), 95% CI)
Out-of-hours cooperation among community health care providers		
Positive	33 (14, 10–19)	11 (20, 11–32)
Neutral	106 (45, 39–52)	40 (71, 58–82)
Not interested	82 (35, 29–41)	5 (9, 4–19)
Palliative care consultation service		
Want regular outreach visits	56 (24, 19–30)	23 (41, 29–54)
Want on-demand consultation	101 (43, 37–49)	29 (52, 39–64)
Not interested	63 (27, 22–33)	4 (7, 3–17)

CI = 95% confidence interval.

response to this question in our study. Taken together, these findings show that about 70% of GPs around the world believe that palliative care is one of their essential tasks, but the remaining 30% are unwilling to care for terminally ill cancer patients because of the balance between other occupational and personal responsibilities and/or lack of interest.^{12,13} Development of a regional system, therefore, should be intended to support those GPs who already care for terminally ill cancer patients at home or are interested in caring for such patients so that they see more patients with a minimum increase in their workload. To increase the total number of GPs in the community with interest in palliative care might require political or social intervention strategies.

The second important finding of this study is the clarification of the availability of symptom control procedures in Japan. District nursing services reported a variety of opioids available, but 35% of GPs reported that oral opioids were unavailable, even if expert advice was available, and 50% reported that

subcutaneous opioids or haloperidol were unavailable. In contrast, previous studies from Australia and the U.K. demonstrated that GPs were, in general, familiar with the use of opioids but less confident or experienced difficulties dealing with psychiatric symptoms and/or the use of home care technology.^{11,12,14} Possible interpretations of these findings are the strict regulation of opioids in the community in Japan, the lack of opportunity in medical education regarding opioid medications, and the lack of a coordinated system to support home care technology.²² Although peripheral intravenous infusion was available in many situations for medically assisted hydration at home, hypodermoclysis was less readily available despite existing evidence that hypodermoclysis is more convenient and safer than intravenous access.²³ In addition, the fact that drainage of ascites or pleural effusion and transfusions were unavailable in 50% of GP clinics and district nursing services could be partly because they are time-consuming procedures and not only the result of

Table 5
Reasons for Admission of Terminally Ill Cancer Patients After Care at Home From the District Nurse's Perspective (n = 115)

Reason for Admission	None n (%), 95% CI)	Rarely n (%), 95% CI)	Sometimes n (%), 95% CI)	Often n (%), 95% CI)	Always n (%), 95% CI)
Physical symptoms	9 (8, 4–14)	28 (24, 17–33)	32 (28, 20–37)	32 (28, 20–37)	5 (4, 2–10)
Delirium	17 (15, 9–22)	38 (33, 25–42)	24 (21, 14–29)	27 (23, 17–32)	9 (8, 4–14)
Concern about out of hours	48 (42, 33–51)	17 (15, 9–22)	18 (16, 10–23)	18 (16, 10–23)	5 (4, 2–10)
Unexpected change in physical condition	6 (5, 2–11)	20 (17, 12–25)	32 (28, 20–37)	41 (36, 27–45)	8 (7, 4–13)
Family physician absent or inaccessible out of hours	46 (40, 31–49)	25 (22, 15–30)	19 (17, 11–24)	15 (13, 8–20)	4 (4, 1–9)
Lack of home care nurses	67 (58, 49–67)	21 (18, 12–26)	11 (10, 5–16)	7 (6, 3–12)	1 (1, 0–5)
Lack of informal caregivers	38 (33, 25–42)	32 (28, 20–37)	25 (22, 15–30)	8 (7, 4–13)	4 (4, 1–9)
Family burden of caregiving	5 (4, 2–10)	17 (15, 9–22)	24 (21, 14–29)	55 (48, 39–57)	10 (9, 5–15)

95% CI = 95% confidence interval.

difficulties in monitoring potential adverse effects. This survey thus suggests that potentially useful strategies to increase the availability of palliative care procedures at home should include 1) basic education of GPs about opioids, psychiatric medications, and hypodermoclysis; 2) developing a system to support home care technology, such as subcutaneous infusion; and 3) research to establish feasible methods to manage ascites or pleural effusion at home.^{24,25}

The third important finding of this study related to the level of willingness of GPs and DNs to participate in out-of-hours cooperation among community health care providers and palliative care consultation services in the community. In general, responses were more positive with the latter rather than the former. Taking into account the fact that concern about out of hours and family physician absence or inaccessibility out of hours were not listed as main reasons for admission in this survey, the development of a system of cooperation among community health care providers out of hours would be difficult because of legal or political regulations, potential conflicts of interest, and personal conflicts. Yet, community palliative care consultation service is one of the most commonly demanded services by GPs,^{13,15} and some research evidence has recently emerged about the effectiveness of community-based palliative care consultation activities.^{26,27} Development of a community palliative care team and continuing information is vital because one study revealed that GPs are often unaware of such regional consultation systems even after they are established.¹³

The fourth important finding of this study clarifies the views of DNs regarding reasons for admission of terminally ill cancer patients after they have been cared for at home. In this survey, the most frequent reason for admission was family burden of caregiving, followed by unexpected change in physical condition, uncontrolled physical symptoms, or delirium. This finding is generally consistent with previous views suggesting that useful strategies to avoid unnecessary admission to hospital include alleviating the family caregiving burden. For example, the comprehensive arrangement of regional resources including respite care and day care as well as improvements in symptom

control has been previously suggested.^{7,10,14,15} Our findings stress that, in addition to symptom control, alleviating the burden of family care is essential for the development of a community palliative care program.

This study has several limitations. First, the response rate of this study, especially from GPs, was low. Our findings, therefore, are possibly not representative of all Japanese GPs and DNs. This can be a significant cause of bias, but we believe there would be no reliable means to increase the response rate because national physicians surveys, even conducted by the Japan Medical Association (representative organization of the GPs), obtained a generally low response rate (37%).¹⁹ In addition, we have no accessible data on clinic physician backgrounds, and comparisons between respondents and non-respondents or all GPs are impossible. Second, as the study focused on cancer patients, we cannot make conclusions about palliative care for noncancer populations.

In conclusion, in Japan, over half the GPs have no exposure to cancer patients dying at home per year, and the remaining half see a small number of terminally ill cancer patients at home. Oral opioids, subcutaneous opioids, and haloperidol were unavailable in 30% to 50% of GP clinics, whereas more than 90% of the district nursing services had access to them. GPs and DNs were willing to use community palliative care consultation services if available, and common reasons for admission to hospital were the family burden of caregiving and uncontrolled symptoms. Potentially effective strategies to develop a regional palliative care program should include basic education of GPs about opioids and psychiatric medications, easily available on-demand consultation services from palliative care experts, a system to support home care technology such as subcutaneous infusion, and development of a community care system to alleviate the burden of care for family members.

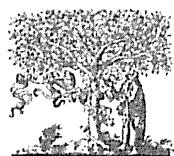
Disclosures and Acknowledgments

This study was funded by the Health and Labor Sciences Research Grants for Third Term Comprehensive Control Research for Cancer,

Japan. The authors made no other financial disclosures and declare no conflicts of interest.

References

1. Steinhilber KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
2. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007;18:1090–1097.
3. Smeenk FW, van Haastregt JC, de Witte LP, Crebolder HF. Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: systematic review. *BMJ* 1998;316:1939–1944.
4. Finlay IG, Higginson IJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol* 2002;13(Suppl 4):257–264.
5. Ministry of Health, Labour and Welfare. Population survey report 2005. Available from <http://www.e-stat.go.jp/SG1/estat/List.do?lid=000001066473>. Accessed February 10, 2011.
6. Cohen J, Houttekier D, Onwuteaka-Philipsen B, et al. Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol* 2010;28:2267–2273.
7. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–521.
8. Fukui S, Fukui N, Kawagoe H. Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: a nationwide survey. *Cancer* 2004;101:421–429.
9. Fukui S, Kawagoe H, Sakai M, et al. Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. *Palliat Med* 2003;17:445–453.
10. Jack B, O'Brien M. Dying at home: community nurses views on the impact of informal carers on cancer patients' place of death. *Eur J Cancer Care (Engl)* 2010;19:636–642.
11. Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 2002;16:457–464.
12. Rhee JJ, Zwar N, Vagholkar S, et al. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *J Palliat Med* 2008;11:980–985.
13. Burt J, Shipman C, White P, Addington-Hall J. Roles, service knowledge and priorities in the provision of palliative care: a postal survey of London GPs. *Palliat Med* 2006;20:487–492.
14. Groot MM, Vernooij-Dassen MJ, Verhagen SC, Crul BJ, Grol RP. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliat Med* 2007;21:697–703.
15. Barclay S, Todd C, McCabe J, Hunt T. Primary care group commissioning of services: the differing priorities of general practitioners and district nurses for palliative care services. *Br J Gen Pract* 1999;49:181–186.
16. Groot MM, Vernooij-Dassen MJ, Crul BJ, Grol RP. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliat Med* 2005;19:111–118.
17. Burt J, Shipman C, Addington-Hall J, White P. Nursing the dying within a generalist caseload: a focus group study of district nurses. *Int J Nurs Stud* 2008;45:1470–1478.
18. Dunne K, Sullivan K, Kernohan G. Palliative care for patients with cancer: district nurses' experiences. *J Adv Nurs* 2005;50:372–380.
19. Miyashita M, Morita T, Uchida T, Eguchi K. Knowledge about opioid treatment in 97,961 Japanese physicians. [abstract]. *J Clin Oncol* 2010;28(Suppl):e16523.
20. Japan Medical Association. Survey of physician attitude toward palliative care [in Japanese]. 2008.
21. Yamagishi A, Morita T, Miyashita M, et al. Palliative care in Japan: current status and a nationwide challenge to improve palliative care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. *Am J Hosp Palliat Care* 2008;25:412–418.
22. Ise Y, Morita T, Maehori N, et al. Role of the community pharmacy in palliative care: a nationwide survey in Japan. *J Palliat Med* 2010;13:733–737.
23. Martin CM. Hypodermoclysis: renewed interest in an old technique. *Consult Pharm* 2010;25:204–206, 209–212.
24. Alisky JM. Implantable central venous access ports for minimally invasive repetitive drainage of pleural effusions. *Med Hypotheses* 2007;68:910–911.
25. Po CL, Bloom E, Mischler L, Raja RM. Home ascites drainage using a permanent Tenckhoff catheter. *Adv Perit Dial* 1996;12:235–236.
26. Teunissen SC, Verhagen EH, Brink M, et al. Telephone consultation in palliative care for cancer patients: 5 years of experience in The Netherlands. *Support Care Cancer* 2007;15:577–582.
27. Imura C, Fujimoto K, Nozue Y, et al. Outreach program of palliative care team. [in Japanese]. *Gan To Kagaku Ryoho* 2010;37:863–870.



Research report

The relationships between complicated grief, depression, and alexithymia according to the seriousness of complicated grief in the Japanese general population

Minako Deno^{a,*}, Mitsunori Miyashita^b, Daisuke Fujisawa^c, Satomi Nakajima^d, Masaya Ito^{d,e}

^a Correspondence Division, Musashino University, Japan

^b Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Japan

^c Psycho-oncology Division, National Cancer Center East, Japan

^d National Institute of Mental Health, National Center of Neurology and Psychiatry, Japan

^e Japan Society for the Promotion of Science, Japan

ARTICLE INFO

Article history:

Received 31 May 2011

Accepted 28 June 2011

Available online 29 July 2011

Keywords:

Complicated grief

Alexithymia

Depression

Bereavement

Emotion

ABSTRACT

Background: The present research investigated whether the relationship between alexithymia and complicated grief was different from the relationship between alexithymia and general depressive symptom according to the seriousness of complicated grief in the Japanese general population.

Methods: In the Japanese general population sample, 948 participants between 40 and 79 years old (effective response rate, 48.0%) completed a cross-sectional anonymous questionnaire about alexithymia, depression, and complicated grief. To compare the high risk ($n = 243$) and low risk ($n = 705$) of complicated grief groups, simultaneous analysis of two groups with standard maximum likelihood estimation was performed and six hypothesized models were verified.

Results: The model ($RMSEA = 0.047$, $AIC = 71.520$) that showed that the path coefficients of the latent variable of alexithymia to the observed variables were equal and that the path coefficient of alexithymia to psychological distress was equal was adopted. The contribution ratios from alexithymia to complicated grief were apparently smaller (2–4%) than those to depression (37–38%).

Conclusions: Our findings showed that alexithymia scarcely contributed to complicated grief compared to depression and that the contribution ratio in the high risk group was lower than that in the low risk group. The contribution of the latent variable of psychological distress to complicated grief and depression was lower in the high risk group than in the low risk group. The lack of a correlation between alexithymia and complicated grief might indicate that there are different mechanisms underlying the symptoms of alexithymia and complicated grief.

© 2011 Elsevier B.V. All rights reserved.

1. Introduction

Maciejewski et al. (2007) empirically found that natural psychological responses to grief, such as disbelief, yearning,

anger, and depression, peak within 6 months following the death of significant others. Most people who experience bereavement overcome their natural emotional response to bereavement. However, integration of the loss does not occur and acute grief becomes more intensive and continuous in the form of complicated grief (Shear and Shair, 2005).

Individuals with complicated grief experience a constellation of symptoms that often include preoccupation with the lost person, anger about the death, and avoidance of reminders

* Corresponding author at: Correspondence Division, Musashino University, 3-40-10 Sekimae, Musashino-shi, Tokyo 180-0014, Japan. Tel./fax: +81 422 52 7218.

E-mail address: m_deno@musashino-u.ac.jp (M. Deno).

of the loss (Ogrodniczuk et al., 2005). Although it is widely recognized that symptoms of normal grief are similar to those of depression, there are distinctions between depression and complicated grief in phenomenology, psychophysiology, and responses to treatment (Lichtenthal et al., 2004). Previous research found that complicated grief does not respond well to proven efficacious treatments for depression (Reynolds et al., 1999; Zygmunt et al., 1998). The prevalence rates of complicated grief reported by epidemiological studies on the non-clinical population were 4.2% (Middleton et al., 1996), 24.6% (Chiu et al., 2009), and 2.4% (Fujisawa et al., 2010).

To improve the treatment of complicated grief, it is necessary to investigate the characteristics that effectively buffer complicated grief. Alexithymia, a patient characteristic that influences psychological distress in depression, has been found to influence a patient's response to psychotherapy (McCallum et al., 2003; Taylor, 2000). Ogrodniczuk et al. (2005) found that the negative influence of alexithymia on general symptoms, for example, anxiety, depression, and interpersonal distress, was buffered by psychotherapy. Taylor et al. (1997) found the following three core features of alexithymia: (1) difficulty in identifying feelings, (2) difficulty in communicating feelings, and (3) externally oriented thinking. This three-factor characterization of alexithymia has become the standard for describing the construct (Ogrodniczuk et al., 2005). Of note, alexithymia is not a psychiatric disorder, but rather a characterization of thinking, feeling, and relating processes among patients with a wide range of psychiatric diagnoses.

There has been a sizeable amount of theoretical and empirical work on the relationships between alexithymia and general depressive symptoms (Lipsanen et al., 2004; Ogrodniczuk et al., 2005). Statistically, Lipsanen et al. (2004) demonstrated that depression and alexithymia are highly correlated but distinct. Parker et al. (1991) have summarized the possible causes of overlap between alexithymia and depression as follows. First, the manifestation of alexithymic features might be a transitory reaction (secondary alexithymia) evoked by stressful situations and the accompanying depression and anxiety. Second, secondary alexithymia is a defensive response to the acute depression that typically accompanies stressful situations. Finally, it is a response to overall changes in the quality of life, and not depression per se, that is associated with the manifestation of secondary alexithymia. Furthermore, in some patients, secondary alexithymia may become permanent and indistinguishable from primary (i.e., trait) alexithymia (Parker et al., 1991).

However, few researches have been conducted on the relationship between complicated grief and alexithymia, and none have been conducted in Japan. For example, Ogrodniczuk et al. (2005) found that alexithymia (except for externally oriented thinking) did not correlate with complicated grief, for example, intrusion, pathological grief, and avoidance. A question related to the difference between complicated grief and general depression symptom is as follows: how different is the relationship between the extent of complicated grief and alexithymia from the relationship between depressive symptoms and alexithymia according to the seriousness of complicated grief? The investigation of complicated grief's relationship with alexithymia, which is related to feeling and expressing emotion, will be helpful in understanding and treating complicated grief. In addition, as there are both distinctions and similarities between complicated grief and

depressive symptom, it may be necessary to simultaneously and separately explore how extent complicated grief relates to general depressive symptoms.

The aim of the current study was to investigate whether the relationship between alexithymia and complicated grief differs from the relationship between alexithymia and general depressive symptom according to the seriousness of complicated grief. The hypothesis model of the relationships between alexithymia, depression symptom, and complicated grief is shown in Fig. 1.

2. Methods

2.1. Procedures

A cross-sectional anonymous questionnaire was administered to a sample of the general Japanese population. Four target areas (Tokyo, Miyagi, Shizuoka and Hiroshima prefectures) were identified to obtain a wide geographic distribution for the nationwide sample. The four areas included an urban prefecture (Tokyo) and mixed urban–rural areas (Miyagi, Shizuoka and Hiroshima).

Initially, 5000 subjects aged 40–79 years were identified by a stratified two-stage random sampling method of residents of the four areas. Fifty census tracts were randomly selected for each area and then 25 individuals were selected within each census tract, thus identifying 1250 individuals for each area. Questionnaires were mailed to potential participants in June 2009, and reminder postcards were sent 2 weeks later. The ethical and scientific validity of this study was confirmed by the institutional review boards of graduate medicine in Tokyo University.

2.2. Measures

Alexithymia was assessed by the Japanese version of the Toronto Alexithymia Scale-20 (TAS-20) (Bagby et al., 1994; Komaki et al., 2003). This scale is a self-report questionnaire that is constructed by the following three factors: "difficulty identifying feelings", "difficulty describing feelings", and "externally oriented thinking." Twenty items are asked, using a five-point Likert scale (1: absolutely disagree, 2: somewhat disagree, 3: neutral, 4: somewhat agree, and 5: absolutely agree). Content and concurrent validity and reliability of this scale were confirmed.

Complicated grief was assessed by the Brief Grief Questionnaire (BGQ) (Shear et al., 2006). The BGQ is a five-item, self-report questionnaire that inquires about difficulty accepting death, interference of grief in their life, difficulty of

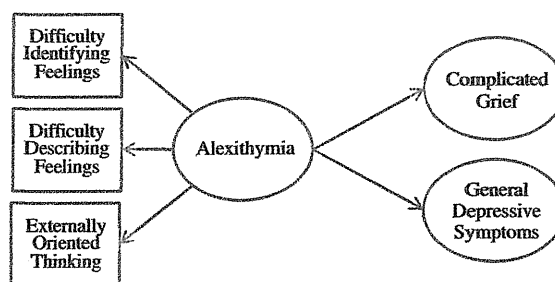


Fig. 1. Hypothesis model for the relationship between alexithymia and complicated grief.

images or thoughts of death, avoidance of things related to the deceased, and feeling cut off or distant from other people. The answers are rated as 0, not at all; 1, somewhat; or 2, a lot. A past report suggests that a total score on the BGQ of 8 or higher is indicative of complicated grief; between 5 and 7 of probable complicated grief; and less than 5 of no complicated grief (Shear et al., 2006). A diagnosis of complicated grief should not be given within six months after bereavement (Prigerson et al., 2009); therefore, those who had experienced bereavement within the past six months were excluded. In addition, those who had experienced bereavement with their children were also excluded because grief over children's death has been consistently reported to be prolonged, and the diagnostic reliability of complicated grief among this population has been questioned (Dyregrov et al., 2003; Stroebe et al., 2007).

General depressive symptom was assessed by K6 (Furukawa et al., 2003; Kessler et al., 2002). K6 is a six-item self-assessment scale that measures the extent of decreasing self-esteem and feelings of depression and hopelessness. The answers are rated on a five-point Likert scale. Content and concurrent validity and reliability of this scale were confirmed.

Demographic data were obtained including age, gender, time of recent bereavement, relationship with the deceased, cause and place of death of the deceased, and days spent with the deceased during the last week of the end-of-life period, whether the bereavement was expected or not, and whether the participant had been a caregiver of the deceased or not.

2.3. Participants

Of the 5000 questionnaires that were distributed, 44 were undeliverable and 1975 were returned (Response rate: 39.9%). Of these, 117 were excluded due to missing data. Of the remaining questionnaires, 792 were excluded because the respondents had not experienced bereavement within the past ten years, 114 because of bereavement within the past six months, and 4 because of bereavement with their children. Thus, 948 responses were analyzed (effective response rate, 48.0%).

2.4. Statistical analysis

The presence of complicated grief was defined using the abovementioned cutoff score, according to previous research (Shear et al., 2006). Using PASW version 18 (Polar Engineering and Consulting, 2009), ANOVA was conducted to investigate differences in complicated grief by demographic variables and factors related to bereavement.

To investigate whether the relationship between alexithymia and complicated grief differs from the relationship between alexithymia and depressive symptom according to the seriousness of complicated grief, a simultaneous analysis of two groups was performed with AMOS version 18 (Arbuckle, 1983–2009), with standard maximum likelihood estimation. Six hypothesized models were compared. The models were as follows: model 0: all parameters are different between two groups; model 1: the path coefficients of the latent variable of alexithymia to observed variables are equal; model 2: the path coefficients of the latent variable of psychological distress to observed variables are equal; model 3: in addition to model 1,

the path coefficients of the latent variable of psychological distress to observed variables are equal; model 4: in addition to model 1, the path coefficient of alexithymia to psychological distress is equal; and model 5: in addition to model 3, the path coefficient of alexithymia to psychological distress is equal.

Indices of fit of the model to the data were evaluated with several statistics: goodness of fit index (GFI) of .95 or greater, adjusted goodness of fit index (AGFI) of .90 or greater, the comparative fit index (CFI) of .95 or greater, the root mean square error of approximation (RMSEA) less than or equal to .05, a chi-squared that was not significant ($p > .05$), and Akaike's Information Criterion (AIC).

3. Results

According to previous research, the participants were divided to three groups: high risk of complicated grief ($n = 25$), probable complicated grief ($n = 218$), and low risk of complicated grief ($n = 705$). It might be appropriate to compare three groups; however, the high risk group of complicated grief with the group of probable complicated grief were combined and regarded as the high risk group (a score of 5–10) because the number of participants in the high risk group of complicated grief was insufficient for conducting simultaneous analysis. In the present results, we compared two groups: the high risk of complicated grief ($n = 243$) and low risk of complicated grief ($n = 705$).

The results of the ANOVA that investigated differences by demographic variables and factors related to bereavement are shown in Table 1. Females experienced higher complicated grief than males ($t(918) = -2.675, p < .01$). Of the factors related with bereavement, the relationship with the deceased ($F(4, 943) = 22.300, p < .001$), primary caregiver ($t(929) = 6.229, p < .001$), cause of death ($F(3, 941) = 13.072, p < .001$), place of death ($F(4, 943) = 3.653, p < .01$), expected death ($t(866) = -3.369, p < .001$), and days spent with the deceased during the end-of-life period ($F(3, 864) = 13.001, p < .001$) were significant. Age and time since bereavement were not statistically significant. As for the relationship with the deceased, spouses of the deceased experienced the highest complicated grief compared to the other groups. Parents and siblings of the deceased experienced higher complicated grief than parents-in-law and others. There were no significant differences between parents and siblings or between parent-in-laws and others. Primary caregivers scored higher on complicated grief than those who were not primary caregivers. Cancer and cardiac disease caused more serious complicated grief than other causes of death. As for the place of death, those who lost their significant person in a care facility experienced higher complicated grief than others. In addition, the group of unexpected death experienced a higher complicated grief score than expected death. Among the groups of days spent with the deceased, the groups of everyday and 4–6 days per week scored higher on complicated grief than the groups of 1–3 days per week and none.

Pearson's correlation coefficients between variables are shown in Table 2. The results showed that the correlation coefficients between complicated grief and general depressive symptoms were significant (the high risk group; $r = 0.211$, the low risk group; $r = 0.190$, the same order shall apply hereinafter). To avoid modeling the subscales of complicated grief and

Table 1

The relationships of demographic variables/factors related to bereavement and complicated grief (n = 948).

	n	Mean	SD	F or t
<i>Gender</i>				
Male	387	2.76	2.05	$t(918) = -2.675^{**}$
Female	533	3.14	2.19	
<i>Age</i>				
40–49	215	2.90	2.24	$F(3, 926) = 0.676$
50–59	340	2.98	2.07	
60–69	363	3.04	2.18	
70–79	12	3.74	2.39	
<i>Relationship with the deceased</i>				
Spouse	62	4.85	1.76	$F(4, 943) = 22.300^{***}$
Parent(s)	458	3.11	2.19	
Parent(s)-in-law	245	2.41	1.86	
Sibling(s)	88	3.65	2.15	
Others	95	2.32	2.14	
<i>Primary caregiver</i>				
Yes	457	3.46	2.18	$t(929) = 6.229^{***}$
No	487	2.59	2.07	
<i>Time since bereavement</i>				
6–12 months	110	3.04	2.11	$F(9, 938) = 0.864$
1–2 years	140	3.26	2.31	
2–3 years	135	2.83	2.13	
3–4 years	117	2.80	2.17	
4–5 years	87	2.98	2.20	
5–6 years	84	2.89	2.13	
6–7 years	96	3.12	2.10	
7–8 years	60	2.88	2.31	
8–9 years	48	2.90	2.04	
9–10 years	71	3.45	2.08	
<i>Cause of death</i>				
Cancer	350	3.42	2.20	$F(3, 941) = 13.072^{***}$
Stroke	94	2.99	2.22	
Cardiac disease	110	3.46	2.08	
Others	391	2.52	2.04	
<i>Place of death</i>				
Home	173	2.88	2.13	$F(4, 943) = 3.653^{**}$
General hospital	645	3.06	2.15	
Hospice/PCU	32	3.41	2.34	
Care facility	62	2.27	2.09	
Others	36	3.84	2.31	
<i>Expected death</i>				
Expected	564	2.84	2.13	$t(866) = -3.369^{***}$
Unexpected	304	3.36	2.20	
<i>Days spent with the deceased during the end-of-life period</i>				
Everyday	215	3.62	2.25	$F(3, 864) = 13.001^{***}$
4–6 days/week	93	3.61	2.12	
1–3 days/week	221	2.80	2.00	
None	339	2.62	2.13	

** $p < .01$, *** $p < .001$.

general depressive symptoms as factors of alexithymia, an underlying latent variable labeled “psychological distress” was assumed. Also, we assumed that “alexithymia” was the underlying construct between difficulty identifying feelings, difficulty describing feelings, and externally oriented thinking because of the high correlation coefficients between them ($r = 0.340$ – 0.618 and $r = 0.415$ – 0.650 , respectively).

The fit indices of these models are shown in Table 3. As shown in Table 3, model 4 (with RMSEA = 0.047, AIC = 71.520)

yielded values smaller than the values of the other models, and thus was the correct result. Model 4 showed that the path coefficients of the latent variable of alexithymia to observed variables were equal and that the path coefficient of alexithymia to psychological distress was equal. The standardized path coefficients are shown in Fig. 2. The standardized indirect effect coefficients (contribution ratio) from alexithymia to complicated grief were 0.200 (4%) in the low risk group of complicated grief and 0.137 (2%) in the high risk of complicated grief group. The standardized indirect effect coefficients (contribution ratio) from alexithymia to general depressive symptom were 0.608 (37%) in the low risk of complicated grief group and 0.616 (38%) in the high risk of complicated grief group. Overall, the final model accounted for 66% of the variance in the latent variable of psychological distress.

4. Discussion

The results of the current study have advanced our understanding of the relationship between alexithymia, complicated grief, and general depressive symptom in the Japanese general population. The findings showed that the relationship between alexithymia and complicated grief differed according to the seriousness of complicated grief. In other words, alexithymia scarcely contributed to complicated grief, especially in the high risk of complicated grief group, and the contribution ratio in the high risk group was lower than in the low risk group. In addition, the relationship of complicated grief and general depressive symptom with alexithymia differed in both groups, as previous research has shown (Ogrodniczuk et al., 2005). The contribution of the latent variable of psychological distress to complicated grief and general depressive symptoms was lower in the high risk group than in the low risk group.

As for demographic variables and factors related to bereavement, the present results supported previous research. First, the complicated grief score was significantly related to gender, which is consistent with previous research (Boelen et al., 2006). However, because some research did not find a gender difference (Boelen and van den Bout, 2003), further investigation is necessary. Second, the relationship with the deceased was an important factor of complicated grief, which supported the previous research that indicated the important role played by close kinship in complicated grief (Gana and K'Delant, 2011; Johnson et al., 2007). The present result suggested that spouses of the deceased experienced the highest complicated grief, whereas, there was no significant difference between parents-in-law and others. Therefore, the impact of the death of significant others was likely influenced by the degree of kinship or direct blood relationships. Finally, as for primary caregivers and days spent with the deceased, these variables might be related to each other. All of these variables were quantity (not quality) aspects of the relationship with the deceased. Thus, primary caregivers might be those who were close relatives and might have spent more time with the deceased.

Interestingly, alexithymia, which had been found to influence patients' response to psychotherapy (Ogrodniczuk et al., 2005), showed different relations to complicated grief according to the seriousness of complicated grief. It suggests that, in the high risk group of complicated grief, alexithymia may not directly influence the improvement of complicated grief. In